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## Introduction

Recent molecular studies have identified two large genes, BRCA1 on chromosome 17 and BRCA2 on chromosome 13; mutations in these genes are now thought to be responsible for the majority of breast cancer cases in families with four or more affected relatives (Ford et al., 1995). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (Struwing et al., 1997; Whittemore et al., 1997; Schrag et al., 1997). There are several benefits associated with genetic testing for breast cancer susceptibility (Baum et al., 1997). For example, women found to be mutation carriers can increase the probability that breast cancer will be detected at early stage by increasing their breast cancer surveillance behavior and women who learn that they do not carry a cancer-predisposition mutation may experience relief and improvements in quality of life (Baum et al., 1997). However, genetic testing can also have adverse psychological consequences including loss of insurance, stigmatization, and increased psychological distress (Croyle et al., 1997; Bankowski et al., 1991, Holtzman, 1989). Most of the studies of the impact of counseling and genetic testing have predominantly focused on Caucasian women and have paid little attention to the role of ethnicity. Several lines of research suggest that minority women may have different attitudes toward genetic testing and that they may react differently to notification of test results. For example, African-American women have less knowledge about cancer (Michieuet et al., 1982), they utilize screening methods for breast cancer less often (Vernon et al., 1991; Powell et al., 1990) and they have higher levels of cancer anxiety (Miller et al., 1994). Furthermore, African-American women believe that they have less control over their health (Miller & Hailey, 1994), and they have been found to have strong fatalistic attitudes toward cancer and cancer treatment (Bloom et al., 1987). These findings suggest that African-American women may also differ in their attitudes about genetic testing. In order for genetic testing to be successfully implemented in this population, it is important to: 1) identify factors that predict interest in testing; 2) examine the impact of genetic counseling on interest in genetic testing; and 3) measure the impact of risk notification on psychological adjustment and screening behaviors.

The present study examines these issues among urban women of African descent. The aims of the study are to: 1) identify factors that are associated with interest in genetic testing. 2) demonstrate the psychological effects of genetic counseling for women with family history of breast cancer; 3) measure the impact of risk notification based on genetic testing and its effects on psychological functioning and preventive and early detection behaviors. To achieve these aims, three interrelated studies are being conducted. Study 1 is a cross-sectional study examining factors influencing interest in and readiness to undergo genetic testing. Study 2 is a longitudinal investigation of whether genetic counseling increases knowledge and promotes readiness to undergo genetic testing. Study 3 consists of pre- and post-notification evaluation of the psychosocial impact of DNA testing.

## Body

### Procedure:

African-American women scheduled for an appointment at the Breast Examination Center of Harlem (BECH) are being recruited. At the time of their visit the research assistant explains the study to eligible women and Survey 1 along with the consent form is mailed to interested women.

Once the women have completed Study 1, they become eligible for Study 2. Women who are at high risk for breast cancer are invited to receive individual genetic counseling and women who are at low risk for developing breast cancer are invited to participate in professionally-led group discussion. Women who express an interest in genetic testing after their counseling session are offered to donate a blood sample for BRCA testing. Approximately 2 weeks after their genetic counseling Survey 2 is mailed to the women. Participants who decide not to receive the genetic counseling are mailed copy of Survey 2 to complete at time points comparable to individuals who undergo counseling.

Once the women have completed Study 2, they become eligible for Study 3. Subjects who elect to receive their test results are informed in accordance with IRB approved protocol (i.e., appropriate post-test counseling is provided). To assess acute distress and to monitor participants' well-being following notification, brief psychological measures are administered immediately after subjects notification session and again 10 days later. Follow-up surveys are mailed to all women approximately 1 (survey 3a), 6 (Survey 3b), and 12 (Survey 3c) months after their notification session.

Recruitment: To-date 137 (57 since last report) women have signed the consent form. Ninety-five women have undergone genetic counseling and 53 women have donated a blood sample for BRCA testing. As described in detail in the previous progress reports we are behind in subject recruitment because of several problems encountered during the first 2 years of the study. As indicated in the progress report for 1998 our main effort is now directed at attaining our goal of recruiting 200 high risk women. We do anticipate that we will be able to attain this goal. However, as we need to analyze the data and write manuscripts for publication we are requesting a one year no-cost extension.

Preliminary Results: Psychosocial predictors of genetic testing. Baseline data has been entered and verified for 81 women who were offered both free counseling and BRCA testing. Thirty-two (39.5%) declined testing and 49 women underwent testing (60.5%). Surprisingly, when test results were available, 8 (16.3%) women declined to learn their test results. This is a significantly higher refusal rate than we have observed in our studies with White women where 98.4% of the women who donated a blood sample elected to learn their test results. Consistent with previous studies with White women, African-American women who declined testing/results perceived their breast cancer risk to be higher and reported higher levels of intrusive thoughts

about breast cancer than women who elected to learn their test results. In addition, women who declined testing/results were significantly: 1) more worried about their emotional reactions if they were found to be mutation carriers; and 2) more likely to indicate that if they were found to be mutation carriers they would feel less healthy than other people, singled out, and be ashamed. No differences were observed in demographic variables or anxiety and depression levels. These findings indicate that genetic counseling needs to address these women's emotional issues as well as their concerns that they might be stigmatized if they are found to carry a BRCA1/2 mutation. These findings have been submitted for presentation at the Society of Behavioral Medicine and will be submitted for publication.

Preliminary results: High frequency of sequence variants in women of African descent undergoing BRCA1 or BRCA2 testing. Mutation data are available from 57 individuals from 49 families who underwent BRCA1 and/or BRCA2 testing. Of the 53 individuals from 49 families who underwent BRCA1 coding sequence analysis, 5 individuals (9.4%) from 5 families (10.2%) were heterozygous for presumably deleterious BRCA1 mutations. An additional 21 BRCA1 sequence variants of uncertain significance were detected in 16 individuals (30.2%) from 16 families (32.7%). BRCA2 sequence analysis was performed on 33 individuals from 28 families (4 individuals tested only for previously identified mutations). Of the 29 individuals from 28 families undergoing complete BRCA2 coding sequence analysis, 2 (6.9%) were found to carry presumably deleterious mutations. An additional 17 individuals (58.6%) from 16 families (57.1%) were found to carry a total of 28 BRCA2 sequence variants of uncertain significance. Of 29 individuals (28 families) undergoing both BRCA1 and BRCA2 analysis, 21 persons (72.4%) from 20 families (71.4%) had at least one sequence variation of uncertain significance. More than one variant was noted in 17 individuals from 16 families. Several variants (3 BRCA1, 5 BRCA2) were observed in more than 1 family. These findings indicate that prevalence of genetic variants of uncertain significance must be taken into account when providing counseling regarding BRCA testing to individuals of African descent. Robson M, Duteau-Buck C, Valdimarsdottir H, Guevarra J, Baum R, Hull J et al. American Journal of Human Genetics 1999.

### **Conclusion**

To date 137 women have signed the consent form. As we anticipate that we will be able to recruit approximately 50 high risk women during the last year of the study we will be able to attain our goal of recruiting 200 high risk women. However, in order to complete data verification and to prepare manuscripts for publications we are requesting a one year no-cost extension. Our preliminary findings indicate that genetic counseling needs to address African-American women's concerns that they might be stigmatized if they are found to carry a BRCA1/2 mutation and counseling needs to take into account the possibility that BRCA1/2 mutations of unknown biological and clinical significance may be identified.

With the support from this grant we have one published paper, one paper submitted, and two published abstracts.

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## Cancer-Specific Distress is Related to Women's Decisions to Undergo BRCA1 Testing

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### Problem

To examine the role of demographic variables, objective risk, perceived risk and cancer-specific distress in women's decisions to undergo genetic testing

### Methods

One-hundred and five women with family histories of breast cancer completed a baseline questionnaire after which they were invited to attend a genetic counseling session and provide a blood sample for BRCA1 testing

### Results

Fifty-five percent of the participants provided blood samples. After controlling for age, objective risk and perceived risk, which were positively related to provision of blood sample, women with moderate levels of cancer-specific distress were more likely to provide a blood sample than women with high or low levels of cancer-specific distress.

### Conclusions

Cancer-specific distress affects women's decisions to undergo genetic testing for BRCA1. Genetic counseling needs to address cancer-specific distress, since it may affect the probability that individuals are making an informed decision about undergoing genetic testing for breast-cancer susceptibility.

**Keywords:** BRCA1, Decision-making, Genetic testing, Distress

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## INTRODUCTION

Consistent with risk estimates for most common cancers, women with histories of breast cancer in even one first-degree relative have been found in large epidemiological studies to be more than twice as likely to develop breast cancer themselves (1). A history of additional affected close relatives further increases the risk, as do other characteristics (e.g., bilateral disease, diagnosis at an early age) associated with a role for heredity in the etiology (2,3). Segregation analyses of families with multiple cases of breast and/or ovarian cancer suggest the existence of rare, autosomal dominant susceptibility genes (2,4). Linkage analyses has led to the identification and subsequent cloning of two large genes, BRCA1 on chromosome 17 and BRCA2 on chromosome 13; mutations in these genes are now thought to be responsible for the majority of breast cancer cases in families with four or more affected relatives (2). Depending on the population studied, women with mutation in BRCA1/2 have 40% to 85% cumulative risk of developing breast cancer and 5% to 60% cumulative risk of developing ovarian cancer (5–7).

For women with family histories, there are several benefits associated with genetic testing for breast cancer susceptibility (8). For example, women found to be mutation carriers can increase the probability that breast cancer will be detected at early stage by increasing their breast cancer surveillance behavior (e.g., mammography), or they can decrease the probability that breast cancer will develop by undergoing prophylactic mastectomy (9,10). In addition, women who learn that they do not carry a cancer-predisposition mutation may experience relief and improvements in quality of life (8). However, there are also several negative consequences associated with genetic testing (8). For example, women found to be mutation carriers may face uncertainty about their future, insurance discrimination, and worsened quality of life (11). Consequently, individuals considering genetic testing need to weigh the benefits against an array of possible costs of genetic testing. There are probably several factors that affect individuals' decisions to undergo genetic testing. Intentions to undergo

genetic testing for cancer susceptibility have been found to be related to younger age (12), higher education (12), higher levels of perceived risk (13) and higher levels of cancer-specific distress, as assessed by the intrusion subscale of the Impact of Events Scale, IES (12,14). However, as intention to undergo genetic testing may not result in actual test (15) use, relatively little is known about predictors of actual test use. In two recent studies (16,17), variables found to be positively related to requests for BRCA1 test results included: being a female, younger age, more education, higher levels of objective risk, having health insurance, and higher levels of cancer-specific distress (IES). The participants in these studies were members of hereditary breast ovarian cancer (HBOC) families. They had provided blood samples several years earlier as part of studies conducted to localize the BRCA1 gene, and knew that a BRCA1 mutation had been identified in their family. Therefore, it is not clear if similar results would be obtained with individuals with less extensive family histories of breast cancer and no history of participation in genetic studies.

The possibility that cancer-specific distress may have a different impact on the decision to undergo genetic testing among women with less extensive family histories of cancer is raised by studies that have examined breast cancer screening behavior. These studies have found that high levels of psychological distress, assessed by a variety of measures, were related to reduced compliance with appropriate screening practices, including mammography, clinical breast-examination, and breast self-examination (18–20). On the other hand, there have also been reports that high levels of distress about breast cancer facilitate appropriate screening practices (21,22). It has been suggested (23) that one of the reasons for these apparently contradictory findings is that the relation between distress and screening practices is curvilinear; too much or too little distress may inhibit screening while moderate levels of distress may facilitate screening.

The purpose of the present study was to examine the relation between demographic variables, objective risk, perceived risk, cancer specific-distress and decision making about BRCA1 testing among women



with family histories of breast cancer who had not previously received genetic counseling or participated in genetic studies. Based on the above reviewed literature we expected that education, objective risk, and perceived risk would be positively related to provision of a blood sample for BRCA1 testing. We also expected that women with moderate levels of cancer-specific distress would be more likely to provide a blood sample for BRCA1 testing than women with low or high levels of cancer-specific distress.

## METHODS

### Subjects

Participants were 105 women who were participating in an ongoing longitudinal study examining the psychological and behavioral impact of genetic counseling and testing for breast cancer susceptibility. The women were recruited from two clinics at Memorial Sloan-Kettering Cancer Center, the Special Surveillance Breast Program (SSBP N=62) and the Clinical Genetics Service (CGS, N= 43). To be eligible for the study the women had to: 1) be 18 years of age or older; 2) have at least one first-degree relative diagnosed with breast cancer; 3) have no personal history of cancer; 4) have never undergone genetic counseling for breast cancer; 5) be able to read and write English; and 6) willing to provide informed consent.

### Procedure

Women who were scheduled for a routine mammography at a special surveillance breast clinic or self-referred for genetic counseling were contacted by telephone approximately one to two weeks prior to their scheduled appointment. The study was described as an investigation to learn more about women's attitudes and feelings about breast cancer and genetic testing for breast cancer susceptibility. Participants were told that they would be asked to complete questionnaires several times over the course of the study and that they would have the opportunity to undergo

genetic testing, free of charge to determine whether or not they carry a mutation in the BRCA1 gene. It was emphasized to the women that they could: 1) refuse to participate; 2) discontinue their participation at any time; 3) fill out the questionnaires without going for genetic counseling or genetic testing; 4) attend the counseling session without undergoing genetic testing; and 5) decide not to learn their mutation status once their test results were available. It was also emphasized that the women could not undergo genetic testing unless they had attended the counseling session.

Women who met the study criteria and were interested in participating were mailed a consent form, the baseline questionnaire package, and a pre-stamped envelope. A few days later the women were contacted again by telephone to verify that they had received the questionnaire package, review the consent form, and answer any questions that they might have. The women then returned the signed consent form and the completed questionnaires prior to their genetic counseling visit (see below).

Women at relatively high risk (relative risk  $\geq 2$ ) for breast cancer who had signed the consent form and returned the completed questionnaires were invited to come in for individual genetic counseling. The counseling sessions were conducted by a genetic counselor and lasted one to two hours. After construction of the pedigree, the following issues were addressed: 1) possible reasons for familial clusterings of cancer; 2) the likelihood of the occurrence of cancer in the pedigree to be hereditary (i.e., conforming to the criteria for a hereditary cancer syndrome) or familial (i.e., not meeting those criteria); 3) limitations of pedigree analysis, including the inability to distinguish between a sporadic and inherited cancer; 4) the relative importance of various risk factors other than family history; 5) risk estimates for developing cancer based on family history and/or associated with BRCA mutations; 6) options for prevention and early detection, and their limitations; 5) limitations and benefits of genetic testing for BRCA1; and 6) risks of receiving test results, including insurance discrimination and adverse psychological consequences.

After the genetic counseling, subjects were given the opportunity to provide a blood sample to be tested for mutation in BRCA1. For subjects who decided to undergo genetic testing, a separate informed consent for DNA testing was reviewed and participants were urged to consider the impact of negative, positive, and ambiguous results. It was also stressed that participants could decide not to learn their results once they became available.

Women at relatively low risk for breast cancer (relative risk < 2.0) followed the same procedure as the women at relatively high risk, except they were invited to attend a group genetic counseling session which addressed the same issues as the individual counseling.

## Measures

### *Demographic questionnaires*

Age, education, race/ethnicity and marital status were assessed using a standard self-report form (24).

### *Family history questionnaire*

This questionnaire is designed to assess the occurrence of cancer in participants' biological first- and second-degree relatives. Participants are asked to supply detailed information about their family histories of cancer, e.g., ages of onset and occurrence of multiple cancers. The data from this questionnaire was used by one of us (KB), a genetic counselor kept blind to all other study data, to estimate lifetime objective breast cancer risk.

### *Perceived risk of breast cancer*

Following previously published methods (24–26), subjects rated on a scale from 0% (not at all likely) to 100% (extremely likely) their perceived likelihood of developing breast cancer in their lifetime.

### *Impact of Event Scale (IES)*

The intrusion subscale of the IES (27) was used to assess breast cancer-specific distress. This seven-item subscale assesses frequency of intrusive thoughts about a specific stressor, in this case, the threat of

breast cancer. The coefficient alpha in the present sample was .88, consistent with values reported by Horowitz *et al.*, (27). Subjects indicated how frequently each thought or behavior occurred "during the past week including today". This measure was selected as Lerman, Schwartz *et al.* (17) found that intrusive thoughts about breast cancer were related to BRCA1 test use.

## RESULTS

### **Characteristics of the study population.**

The mean age of the sample was 45.1 years (SD=9.3; range 21 – 72). The majority of the women were white (91%), well educated (75% had attended college) and married (61%). The mean perceived risk was 59.2% (SD=26.5; range 0–100) and the mean objective risk was 28.5% (SD=13.3; range 11%–50%). For the cancer-specific distress measure, the mean score on the IES intrusion subscale was 6.3 (SD=7.5; range 0–31). Fifty-five percent of the participants (N=58) provided a blood sample for genetic testing.

### **Are sociodemographic variables, objective risk and perceived risk related to who provides a blood sample for genetic testing?**

To determine the bivariate correlates of blood provision we conducted a series of  $\chi^2$  analyses. Specifically, we evaluated the associations of sociodemographics, objective risk, and perceived risk with blood provision. Because the distribution for both perceived risk and objective risk was skewed these variables were dichotomized based on a median split. Following the procedure by Lerman and colleagues, (17) age was dichotomized as < 50 vs.  $\geq$  50 years.

As shown in Table I, older women tended to be more likely to provide a blood sample for genetic testing,  $\chi^2$  (1, N=105)=3.4,  $p$  = .06, and women with higher levels of perceived and objective risk were significantly more likely to provide a blood sample for



genetic testing ( $\chi^2(1, N=105)=4.2$ ,  $p=.04$ ;  $\chi^2(1, N=105)=8.0$ ,  $p=.005$  respectively).

TABLE I Bivariate Associations With Provision of a Blood Sample for BRCA1 Testing

Variable	Reference group	% providing blood
Age	< 50	49 <sup>+</sup>
	≥ 50	69
Education	< College	57
	≥ College	55
Marital status	Married	59
	Unmarried	50
% objective risk	< 40	43 <sup>**</sup>
	≥ 40	71
% perceived risk	< 70	48
	≥ 70	68 <sup>*</sup>
Cancer-specific distress	Low distress	52 <sup>**</sup>
	Moderate distress	77
	High distress	38

<sup>+</sup>  $p < .10$  <sup>\*</sup>  $p < .05$  <sup>\*\*</sup>  $p < .01$

### Is cancer specific distress related to who provides a blood sample for genetic testing?

We also evaluated the bivariate association between cancer-specific distress, as measured by the IES intru-

sion subscale, and the provision of a blood sample for genetic testing. In order to examine the hypothesized curvilinear relationship between distress and provision of a blood sample, we categorized scores into low distress (IES 0–1,  $N=46$ ), moderate distress (IES 2–9,  $N=30$ ), and high distress (IES 10+,  $N=29$ ), following the cutoff points established by Lerman and colleagues (17). As shown in Table I, women with moderate distress scores were more likely to provide a blood sample than women with low or high distress scores ( $\chi^2(1, N=105) = 9.25$ ,  $p = .01$ ).

### Is cancer-specific distress related to who provides a blood sample after controlling for demographic and risk variables?

To determine whether cancer-specific distress predicted blood sample provision after controlling for potential confounders, we conducted a logistic regression analysis with hierarchical variable entry. On the first step we entered all of the variables with significant ( $p < .10$ ) associations with blood sample provision (age, perceived risk, objective risk). On the second step, we entered cancer-specific distress which was dummy coded with moderate distress serving as the reference cell. The results of this analysis are displayed in Table II.

TABLE II Hierarchical Logistic Regression Predicting Provision of a Blood Sample for BRCA1 Testing

<i>Step and variables</i>	<i>Reference group</i>	$\chi^2$	<i>Odds ratio</i>	<i>95% CI</i>
Step 1				
Age	< 50	14.9	2.4 <sup>+</sup>	6.1, 0.98
	≥ 50			
objective risk	< 40		3.1 <sup>**</sup>	7.3, 1.32
	≥ 40			
perceived risk	< 70		2.1 <sup>+</sup>	5.2, 0.99
	≥ 70			
Step 2				
Cancer-specific distress	Low distress	13.3 <sup>*</sup>	.24 <sup>**</sup>	0.54, 0.11
	High distress		.11 <sup>*</sup>	0.42, 0.03

Note CI=Confidence Interval

<sup>+</sup> $p < .10$ , <sup>\*</sup> $p < .01$ , <sup>\*\*</sup> $p < .001$ .

Age, perceived risk and objective risk, taken together, significantly predicted blood sample provision ( $\chi^2$  change (3, N=105) = 14.9,  $p = .002$ ). Cancer-specific distress, entered on step 2, added significantly to the prediction of blood provision ( $\chi^2$  Change (2, N=105) = 13.32,  $p < .01$ ). Inspection of the final odds ratios supported our prediction of a curvilinear relationship between distress and blood provision. Specifically, women with low levels of cancer-specific distress were less likely to provide a blood sample compared to women with moderate levels of cancer-specific distress (OR=.24, 95% CI=0.5, 0.1). Similarly, women with high levels of cancer-specific distress were less likely than those with moderate levels of distress to provide a blood sample (OR=.11, 95% CI=0.4, 0.03). In addition to cancer-specific distress, objective risk and perceived risk also were independently associated with blood provision (OR=4.4, 95% CI=18.5, 2.7; OR=2.5, 95% CI=6.7, 2.7 respectively). Specifically, women with higher levels of objective risk were about four times more likely to provide blood for genetic testing than women with lower levels of objective risk. In addition, there was a trend suggesting that women with higher levels of perceived risk were more likely to donate blood for genetic testing than women with lower levels of perceived risk.

## DISCUSSION

The results of the present study indicate that cancer-specific distress is related to women's decisions to donate blood for BRCA1 testing. Women with moderate levels of cancer specific distress were more likely to donate blood than women with high or low levels of cancer specific distress. These results were obtained after controlling for age, objective risk and perceived risk, which were all positively related to provision of a blood sample for genetic testing.

The finding of a curvilinear relationship between cancer-specific distress and provision of a blood sample for BRCA1 testing is inconsistent with the finding reported by Lerman and colleagues (17) that individuals with high levels of cancer-specific distress were

more likely to request BRCA1 test results than individuals with moderate or low levels of cancer-specific distress. There are at least three possible explanations for these discrepant findings. First, unlike the subjects in the present study, the participants in the study by Lerman *et al.* (17) included both affected and unaffected male and female members of previously studied HBOC families having extensive histories of breast cancer. Also, unlike participants in the present study who donated blood at the time of the study to learn their mutation status, the members of these HBOC families had donated blood several years earlier as a part of an investigation to localize the BRCA1 gene. Moreover, unlike participants in the present study, the members of the HBOC families were aware that a BRCA1 mutation had been found in their family. It is therefore possible that cancer-specific distress plays a different role in the decision to undergo genetic testing among members of these well-studied high risk families than among individuals in the present study who came from families with much less extensive family histories of breast cancer and who did not know if there was a BRCA1 mutation in their family. Second, cancer-specific distress may differentially affect the decision to provide a blood sample for genetic testing versus the decision to request test results. However, this is an unlikely explanation, as BRCA1 test results are now available for 34 of our participants, and none of them have declined to learn their mutation status. Third, the participants in these two studies could have had different levels of cancer-specific distress (IES). However, this is an unlikely explanation because the cancer-specific distress levels among participants in the present study showed a similar distribution ( $M=6.3$ ,  $SD=7.5$ ) to that reported by Lerman and colleagues (17) ( $M=6.2$ ,  $SD=6.7$ ). The finding in the present study that older women were more likely to provide a blood sample for genetic testing than younger women is also inconsistent with Lerman and colleagues (17) finding that younger women were more likely to request their BRCA1 test results. As with cancer-specific distress, these discrepant results may be due to the fact that the subjects in the present study differed on several variables from the participants in Lerman and colleagues

(17) study. Additional studies are needed to confirm the possibility that psychosocial variables (e.g., cancer-specific distress), as well as demographic variables (e.g., age), may differentially effect the decision to undergo genetic testing depending upon the population studied.

Whether the relationship between distress levels and the decision to undergo testing is linear or curvilinear, the results of the present study support an emerging consensus that distress may be an important variable to consider as we try to understand individuals' decisions to undergo testing. The data reported here revealed a significant relationship between cancer-specific distress levels and testing decisions even after controlling for other previously published predictors (e.g., age, objective risk, perceived risk). Cancer-specific distress has also been found to affect the effectiveness of genetic counseling. Lerman and colleagues (26) found that women who had high levels of cancer-specific distress were more likely to continue to overestimate their lifetime risk of developing breast cancer after the risk counseling than women with low levels of cancer-specific distress. Taken together, the results from these studies and the present study suggest that cancer-specific distress needs to be addressed in the context of genetic testing. Understanding the role of cancer specific-distress in genetic testing will assist in designing interventions which will increase the probability that individuals are making an informed decision about undergoing genetic testing for breast cancer susceptibility and minimize the possible negative psychological impact of genetic testing.

Consistent with previous studies which found that intentions to undergo genetic testing were related to high levels of perceived risk (13,14) the present study found that women with high levels of perceived risk were more likely to provide a blood sample for genetic testing. This finding further indicates the importance of addressing cancer-specific distress, as genetic counseling may not be effective in improving risk comprehension among women with high levels of cancer-specific distress (26).

The results of the present study should be interpreted cautiously for several reasons. First, as a

majority of the women were White and well educated, we can not generalize our findings to individuals from other ethnic and sociodemographic backgrounds. Second, because of the small sample size we could not examine in the logistic regression analyses whether the relation between cancer-specific distress and provision of blood sample differed between women who were recruited from a special surveillance breast program and women who were self-referred for genetic counseling. However, the results from the bivariate analyses, computed separately for each recruitment site, indicated that, at both recruitment sites, women with moderate levels of cancer-specific distress were more likely to provide blood samples than women with low or high levels of cancer-specific distress. Third, the generalizability of these findings to BRCA2 test use needs to be examined as the BRCA2 gene had not been cloned when the present study started.

Despite these limitations, the results of the present study indicate the importance of understanding the role of cancer specific-distress in women's decisions to undergo genetic testing for breast cancer susceptibility.

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**Further Psychometric Validation of the African American Acculturation Scale and  
its Relationship to Breast Self-Examination Frequency**

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Running head: Acculturation and BSE frequency

**Further Psychometric Validation of the African American Acculturation Scale and its  
Relationship to Breast Self-Examination Frequency**

Date Submitted: February 22, 2000

Abstract

The concept of acculturation is one factor that has been used to understand differences in health behaviors between and within a variety of racial and ethnic immigrant groups. Few studies, however, have examined the potential impact of acculturation on health behaviors among African-Americans. The present study had three goals: 1) to re-examine the psychometric properties of the African-American Acculturation scale; 2) to reconfirm relations between acculturation and cigarette smoking; 3) to investigate the impact of acculturation on another type of health behavior, cancer screening, specifically breast self-examination (BSE). African-American women (N=66) attending an inner-city cancer screening clinic completed study questionnaires. Results reconfirmed psychometric properties of the AAAS; replicated the negative association between acculturation and smoking status; and found relations between acculturation and women's adherence to BSE frequency guidelines. Interestingly, a closer examination of the source of the relationship between acculturation scores and BSE frequency suggested that media related items made the major contribution. Findings from this study confirm that there are relations between African American acculturation and health behaviors, including smoking status and adherence to BSE guidelines, and raise the possibility that specific aspects of acculturation may better explain specific health behaviors.

The study of race as a factor in health and illness has a long standing history in biomedical research. However, endeavors to explain differences in health and disease status on the basis of race as a biological indicator are no longer tenable as the scientific and medical community recognizes race to be a classification system constructed by society, not biology (Freeman, 1997). By conceptualizing race as a marker for other differences between groups (e.g. social circumstance, socioeconomic status (SES), cultural values and beliefs), we can obtain more meaningful information with implications for intervention and change. For example, some studies have found that after controlling for socioeconomic status, differences in health behaviors initially accounted for by race either diminish substantially or disappear completely (Breen & Keesler, 1994; Calle, Flanders, Thun, & Martin, 1993; Hiatt et al., 1996). Similar to SES, but less studied in the literature is acculturation, another variable closely linked to race, which may also explain, better, differences between groups as well as differences within groups.

Acculturation refers to the process in which an individual adopts or adheres to attitudes, beliefs, practices, or behaviors congruent with that of the dominant culture. Acculturation is a complex process involving multiple components including phases of acculturation, modes of acculturation, and language usage and fluency as well as numerous ethnic and dominant group moderating variables (Berry, 1980). Not surprisingly, the meaning of acculturation can vary depending on how it is measured or defined. Efforts to operationalize acculturation have recognized the multidimensionality of the construct by incorporating factors such as traditional rituals and practices, food and activity preferences, ethnic composition of one's friendship circle and residential community, values, beliefs, attitudes, and perceived self-identity in addition to



immigration status variables (e.g. place of birth, generational status in U.S., length of residency, and language use and fluency) when calculating a person's level of acculturation. Earlier stages of acculturation measurement research produced scales applicable to more inclusive ethnic and cultural groupings such as Asian-Americans (Suinn, Richard-Figueroa, Lew, & Vigil, 1987), Hispanic Americans (Marin, Sabogal, Marin, & Otero-Sabogal, 1980), and Native Americans (Hoffman, Dana, & Bolton, 1985). More recently, acculturation scales have been designed to appreciate distinctions within ethnic groups by tailoring scales for specific cultural groups, for example, Puerto Ricans (Tropp, Erkut, Coll, Alarcon, & Garcia, 1999), Greek-Americans (Harris & Verven, 1996), Taiwanese aboriginals (Cheng & Hsu, 1995), and Southeast Asians (Anderson et al., 1993).

Although acculturation is a concept that has attracted a great deal of attention in psychological research, only recently, has this construct been examined in the African-American community. According to Landrine and Klonoff (1994), the identification of African-Americans as a racial group, first, and an ethnic or cultural group, second, may explain the relative delay in exploring acculturation in this population. To date, only two scales have been developed to measure acculturation within the African-American population (Landrine & Klonoff, 1994; Snowden & Hines, 1999). The first instrument designed to measure level of African American acculturation, the African American Acculturation Scale (AAAS), was not published until 1994 (Landrine & Klonoff, 1994). The scale assesses eight dimensions of African-American culture theoretically derived to reflect the degree of connection an individual has to African-American culture as opposed to the dominant culture (i.e., White American culture) (Landrine & Klonoff,

1994). Dimensions include: 1) African American religious beliefs and practices; 2) African American family structure and practices; 3) African American socialization; 4) Preparation and consumption of traditional foods; 5) Preference for African American things; 6) Interracial attitudes; 7) Superstitions; and, 8) African American health beliefs and practices. The scale has been reported to be reliable and valid in initial studies by its developers (Landrine & Klonoff, 1994). Importantly, scores on the separate subscales of the AAAS have not been found to be associated with income, social class, or level of education, which also vary by race and/or ethnicity. While preliminary data demonstrates the AAAS to be a viable measure of the acculturation construct, its utility as a research and/or clinical tool is contingent upon its ability to predict other behaviors, performance, or functioning.

Acculturation has been examined increasingly as one of the factors accounting for variation in health behaviors among different cultural groups. For example, acculturation has been found to be positively associated with ever having had a pap test among young Asian-American women (Tang, Solomon, Yeh, Worden, 1999), ever having had a mammography, clinical breast exam (Tang, Solomon, & McCracken, under review), fecal occult blood test, and sigmoidoscopy among older Chinese-American women (Tang, Solomon, & McCracken, unpublished manuscript), greater alcohol consumption among Mexican American women (Alaniz, Treno, & Saltz, 1999), smoking behavior and earlier onset of smoking among Asian-American youth (Chen, Unger, Cruz, & Johnson, 1999), first time and recent mammography or clinical breast exam among Hispanics (O'Malley, Kerner, Johnson, & Mandelblatt, 1999), and illicit drug use among Mexican men and women (Vega, Alderete, Kolody, & Aguilar-Gaxiola,

1998).

Few studies have examined the relationship of acculturation and health behaviors among African-Americans (Landrine & Klonoff, 1994; Klonoff & Landrine, 1999; Brook, Whiteman, Balka, Win, & Gursen, 1997). Of these studies, only two measured acculturation with a validated acculturation scale. Landrine and Klonoff (1996) examined the role of acculturation in cigarette smoking status among 455 African-American men and women ages 18-70 attending, employed, or affiliated with a college campus. The African American Acculturation Scale was used to measure level of acculturation. A significant relationship was found for acculturation and smoking status. Specifically, African Americans who were less acculturated (i.e. identify more strongly with African American culture) were more likely to be smokers. A closer examination of the relationships between the acculturation dimensions and smoking status found significant associations between the family, health, socialization, foods, and superstition subscales and smoking status. African-Americans who were smokers were found to be less acculturated on these subscales were more likely to be smokers.

Results from this initial study on acculturation and smoking status were replicated among a sample of 520 African-American men and women ages 18-79 recruited from residential communities that were identified as predominantly African-American. Similar to the first study, Klonoff and Landrine (1999) found a significant association between the total acculturation score and smoking status with less acculturated African-Americans more likely to be smokers. Also consistent with past findings, significant associations were found for the family, socialization, foods, and superstitions subscales and smoking status. Results from these two studies suggest

that acculturation may play a role in smoking habits among African Americans. To our knowledge, there have been no studies using the AAAS to assess relations between acculturation and any health behavior other than smoking.

The present study examined the role of acculturation in breast self-examination (BSE) behavior. Specifically, we focused on the relationship between acculturation and breast self-examination (BSE) frequency. Although BSE has not been proven unequivocally to be effective in detecting breast cancer or reducing mortality related to the disease, it has been recommended consistently by national clinical societies (e.g. American Cancer Society, American Society of Clinical Oncology) as an important aspect of breast cancer surveillance which has been shown to detect significant number of breast cancers (Porter, 1999). Among economically disadvantaged groups, cost can be a barrier to participating in clinical breast cancer screening (Rimer, 1992). Given that BSE is a cost-free screening procedure that is under a woman's personal control, examining BSE behavior among African American women is particularly relevant. Existing research on BSE behavior among African American women has yielded inconsistent results, with some studies indicating African American women to under-perform BSE (Underwood, 1999) and other studies indicating African American women to over perform BSE (Epstein et al., 1997). While BSE under-performance is well recognized to decrease the efficacy of this screening modality (Coleman, 1991), BSE over-performance is also thought to decrease the utility in women's ability to detect gradual changes in the breast may be compromised (Haagensen, 1952). To date, no study has examined the role of acculturation in BSE frequency. As an example of a self-initiated health promoting behavior, it is important to understand factors

that may encourage or deter BSE among African American women.

The aims of the present study were to re-confirm the psychometric properties and re-establish reliability and validity of the AAAS in an urban, inner city sample of African-American women, to re-examine the relationship of acculturation and smoking status in this population, and to examine the role of acculturation in another health behavior (BSE frequency).

### Methods

Data were gathered as part of a larger ongoing investigation of stress associated with having a family history of breast cancer. Results reported here are from women recruited from an inner city cancer screening clinic who self-identified as African American. Women who self-identified as Caribbean, Hispanic/Black or other ethnic groups were excluded from the present study.

Setting. The Breast Examination Center of Harlem (BECH), a program of Memorial Sloan-Kettering Cancer Center, provides the most advanced, comprehensive diagnostic screening services to members of the Harlem community. All services are provided at no out of pocket expense to the client. Ninety-seven percent of BECH's clientele is Black or Latina. At the time data was collected for this study, BECH's staff was 95% Black or Hispanic. Particularly relevant to this study, nurse practitioners at the BECH give clients instruction on how to properly perform BSE and frequency guidelines (i.e., once a month) are emphasized. Videotaped instructions on how to perform BSE also play repeatedly in the waiting area.

Procedure. Subjects were recruited from the BECH's waiting room on scheduled clinic days by an African American female researcher. After agreeing to participate, all were given an appointment to meet with the researcher three to four weeks afterwards to complete study questionnaires. This schedule

was to ensure that cancer screening results would be received by the subjects prior to the interviews. None of the women received abnormal results. One subject who required a follow-up clinic visit due to unclear or suspicious results was excluded from the study.

On the day of the study appointment, women were met by the researcher who obtained written informed consent. All women completed standardized measures (described in detail below) that assessed African American acculturation and breast self-examination behavior in addition to the measures used in the larger study. As noted by the developers of the AAAS (Landrine & Klonoff, 1996) highly acculturated subjects may find the scale offensive, therefore, care was taken to explain the purpose of the measure to all participants. Participants received \$20 plus the cost of round trip public transportation for the visit.

Subjects. To be eligible participants had to be 25 or older, able to read/write English, able to provide meaningful informed consent, and self-identify as African American. The study excluded women who had a personal history of neoplasm or abnormal pathologic reports or were pregnant. One woman who completed all other questionnaires refused to complete the African American Acculturation Scale; indicating that she did not think the measure was relevant to her experiences. Her data was excluded from these analyses, as was the data of one woman with extreme missing data on the African American Acculturation Scale, resulting in 66 women who completed all measures.

### Measures

Demographic and Medical Questionnaire. A standard questionnaire (Valdimarsdottir et al., 1995) was used to obtain information on age, education, and other demographic variables.

Age ranged between 26 - 72 years. Mean age was 45.00 years with a standard deviation of 10.70 years. Eighty-five percent completed at least some high school. Education was dichotomized into: High School Graduate or Less (N=22); and More Than High School (N=44). Sixty-three percent had a family income between \$10,000-\$39,999, thus income was trichotomized into < \$10,000 (N=12); \$10,000-\$39,000 (N=40); and > \$39,000 (N=14). Sixty-three percent worked either part or full time. Thirty percent were married and 70% were either single, separated, widowed or divorced. Forty-five percent were smokers as indicated by their responses to a question taken from the National Health Interview Survey (Benson & Marano, 1995): "During your lifetime, have you smoked at least 100 cigarettes (5 packs)?" Smoking was unrelated to demographics in this data set. Forty-one percent had at least one first-degree relative (FDR) with breast cancer. It should also be noted that preliminary statistical analyses revealed no associations between FDR status and any other measure in the study.

### Behavioral Measures

Assessment of breast self-examination Two questions, based on published results and modified by the research team, assessed breast self-examination frequency. BSE performance frequency is evaluated over a one year interval, participants were asked: "How often do you perform breast self-examination? (1) *More than once a month*; (2) *Once a month (12 times a year)*; (3) *Every other month (6 times a year)*; (4) *Four or five times a year*; (5) *Two or three times a year*; (6) *Once a year*; (7) *Never*." Under-performance was operationally defined as those women who performed BSE less than once a month. As recent reports (e.g., Epstein & Lerman, 1997) suggest that some women routinely over-perform BSE, (and frequency might be

high following clinical screening visits); a separate question asked about BSE performance over the past three weeks. BSE frequency was not assessed over a one month interval to reduce the possibility that women would be reminded of the appropriate interval and respond accordingly (e.g., demand characteristics). Over-performance in the period following their clinical examination was evaluated with the question: "In the past three weeks, how many times did you perform breast self-examination? (a) *Never* (b) *Once* (c) *2-3 times* (d) *4-5 times* (e) *Six or more times*." Over-performance was operationally defined as performing BSE more than once during the prior three weeks. As would be expected, results on the two measures of BSE frequency were significantly related (chi-square  $F=55.36$ ,  $p < .001$ ).

#### Acculturation Measure

African-American Acculturation Scale (AAAS) (Landrine & Klonoff, 1994). This 74-item measure assesses eight dimensions of African-American culture which are thought to provide an identification of cultural connection (Landrine & Klonoff, 1994). Sub-scales include: 1) Traditional African American Religious Beliefs and Practices (6 Items); 2) Traditional African American Family Structure and Practices (12 Items); 3) Traditional African American Socialization (11 Items); 4) Preparation and Consumption of Traditional Foods (10 Items); 5) Preference for African American Things (11 Items); 6) Interracial Attitudes (7 Items); 7) Superstitions (5 Items); and, 8) Traditional African American Health Beliefs and Practices (12 Items). Answers reported in a Likert-style format which range from (1) Strongly Disagree to (7) Strongly Agree. A subject's score on a sub-scale is computed as the sum of the answers on that sub-scale (e.g., score for the Preference for African American Things sub-scales equals the sum



of the scores on all items for that sub-scale). A Total Summary Score is also computed. Each subject's Total Score equals the sum of the scores on each sub-scale (i.e., the sum of the scores on all 74 items) (Landrine & Klonoff, 1996). A higher score indicates more traditionally African American views. Published reports by the scale's developers have demonstrated the scale's psychometric properties (Landrine & Klonoff, 1994; Landrine & Klonoff, 1996). The scale is newly developed and empirical studies using the AAAS are limited. Studies with data not compiled by the AAAS's developers have not yet been performed to confirm its psychometric properties and concurrent validity.

Subjects were encouraged to complete all items, however, there were missing data. One woman omitted more than 50% of the 74 items and was excluded from these analyses. None of the remaining subjects omitted more than 6 items from the entire measure, and no subject missed more than 3 items from any one sub-scale suggesting that missing items were randomly distributed. Following published procedures of the AAAS's developers, we used mean substitution to replace missing items within sub-scales (Landrine & Klonoff, 1996).

## Results

Phase 1 - In this phase of the study, we examined the psychometric properties and concurrent validity of the AAAS using data from a sample of 35 women who completed the full questionnaire. In addition, we examined relations between AAAS scores and a health behavior (e.g., smoking) previously reported to be associated with those scores (Klonoff & Landrine, 1996). Having confirmed previous findings with the AAAS, we then examined the relations between AAAS scores on that measure and another health behavior not previously examined in

the literature (i.e., breast self-examination frequency).

Consistent with previously published results (Landrine & Klonoff, 1994), data from this sample of African Americans (See Table 1) demonstrated a wide range of scores (e.g., a range of over 250 points on the total AAAS score for this data set and a range of more than 200 points on the total AAAS score found in previously published results). Interestingly, the sub-scale means for this data set differed from the sub-scales means of published results by less than 3 points on every sub-scale, and by less than 5 points on the Total Summary Score (Landrine & Klonoff, 1994). Also consistent with published findings (Landrine & Klonoff, 1994), in this data set the AAAS was not significantly related to demographic variables.

We next examined concurrent validity of the AAAS by following the previously published approach of the scale's developers. They argued that persons of an ethnic group who live in an ethnic-minority neighborhood are likely to be the more traditional members of their culture (because of constant exposure to the culture), whereas those who live in predominately White or integrated neighborhoods are likely to be more acculturated (Landrine & Klonoff, 1994). We followed their published procedures and examined the scores of the answers to the question "I currently live in a Black neighborhood" - (question 68 on the Traditional Socialization sub-scale) and divided the subjects into two extreme groups: 1) The "other residence" group consisted of the women in this sample who circled "This is absolutely not true of me" (N=5); and 2) the "Black neighborhood residence" group who circled "This is absolutely true of me" (N=20). Similar to published results (Landrine & Klonoff, 1994), in MANOVA analyses women who circled "This is absolutely true of me" scored significantly higher (i.e.,

more traditionally African American) than those who answered "This is absolutely not true of me" (i.e., more acculturated) across the eight AAAS sub-scales and the Total Summary Score ( $F = 2.86, p < .034$ ).

Next we examined the relations between acculturation and smoking. MANOVA analyses revealed that smokers ( $N=16$ ) scored higher than non-smokers ( $N=19$ ) across the eight sub-scales and on the Total Summary score ( $F = 2.50, p < .036$ ). Upon closer examination of the data (Table 2), we found significant differences between the smokers and non-smokers on the Family Practices ( $F = 5.14, p < .030$ ) and Interracial Attitudes ( $F = 4.71, p < .037$ ) sub-scales, and on the Total Summary Score ( $F = 5.79, p < .021$ ). These results are generally consistent with the published results of Klonoff and Landrine (1996); and Klonoff and Landrine, (1999) who have reported that the Total Summary Score, as well as the scores on several of the sub-scales, were significantly higher for smokers than those of non-smokers.

Finally, we examined the AAAS scores in relation to BSE frequency. Table 3 shows the eight sub-scales and their relationship to BSE frequency. ANOVA results revealed that the mean for BSE "Under-performers" ( $N= 17$ ) differed from "Others" ( $N=18$ ) on the Preference for African American Things sub-scale, the Socialization summary score and on the Total Summary Score. Women who under-performed BSE (i.e., less than once a month), scored lower on these sub-scales (i.e., more acculturated). The difference on the Preference sub-scale remained significant after Bonferoni correction to reduce possible Type I error associated with assessment of multiple outcomes (i.e.,  $p < .05$  divided by 9 = .005). Consistent with these results, analysis of BSE over performance indicated that "Over-Performers" ( $N=21$ ) also differed from "Others"

(N=14) on the Preference for African American Things and Socialization sub-scales, as well as on the Total Summary Score. We found that women who over-performed BSE scored significantly higher on the Preference sub-scale of the AAAS (i.e., higher scores indicate more traditional African American answers) even after Bonferoni correction. It should be noted that four of the women had responses indicative of habitual under-performance (i.e., generally less than once per month) but over-performed BSE following their clinic visit (i.e., more than once in three weeks). Rerunning the analyses after deleting the few women with potentially inconsistent responses revealed an identical pattern of significance.

To provide additional data on the relationship between scores on the Preference for African American Things sub-scale to BSE frequency, in Phase 2 of the study, an additional 31 women completed only the Preference for African American Things sub-scale (12 items) in addition to the other study measures. The focus on that sub-scale served to reduce subject burden, while providing additional data on the one AAAS sub-scale that indicated a significant relation to BSE frequency in the Bonferoni corrected analyses in Phase 1. Subject characteristics in Phase 1 and 2 did not differ, and the AAAS and demographics were not significantly related.

With a total sample of 66 women, ANOVA analyses again demonstrated a relationship between BSE under-performance and AAAS scores. Confirming what was found in Phase 1, women who under performed BSE scored significantly lower on the Preference for African American Things sub-scale ( $F = 6.42, p < .013$ ); the mean score for "Under-performers" (N=31; mean 45.48, S/D 13.82) versus "Others" (N=35; mean 53.53, S/D 11.98). For over-performance the pattern was again similar to that in Phase 1; the mean Preference scores of "Over-Performers"

( $N=23$ ; mean 56.23 S/D 9.42) was significantly higher than for "Others" ( $N=43$ ; mean 46.28, S/D 14.01) ( $F = 9.29, p < .003$ ).

Given the findings relating Preference scores and BSE frequency, it was of interest to examine the individual items on that sub-scale as a first step in considering potential explanations for the relations (Table 4). For BSE under-performance, there were significant differences on questions 18, 19 and 23. However, using a Bonferoni correction, only question 18 (*i.e., I read, or used to read, Essence magazine*) and question 23 (*i.e., I read, or used to read, Jet magazine*) reached significance. The mean score of women who under-performed BSE was significantly lower on those questions ( $F=10.72$  and  $F=10.26$ , respectively;  $p < .002$  for both questions). For BSE over-performance, significant differences were found on questions 14, 16, 17, 18, 21 and question 23. However, at the Bonferoni corrected level of significance, only question 16 (*i.e., I listen to Black radio stations*) reached significance. The mean score of women who over-performed BSE was significantly higher on question 16 ( $F=10.58$ ;  $p < .001$ ).

### Discussion

The objectives of this study were to re-confirm the psychometric properties and validity of the African American Acculturation Scale (AAAS) (Landrine & Klonoff, 1994) in an independent sample of urban, inner city African American women, to re-examine the relationship between acculturation and smoking status, and to investigate the role of acculturation in breast self-examination (BSE), a cost free, convenient screening modality under a woman's personal control.

Descriptive statistics of scores on the AAAS in our sample were similar to those found in

reports by the scale's developers (Landrine & Klonoff's 1994). We found similar ranges in variability for total acculturation and dimension scores. A similar difference in acculturation by ethnic composition of residential community was also found such that women who lived in a African American community scored higher on the AAAS (i.e. less acculturated) compared to women who lived in a integrated community reconfirming the validity of the AAAS. Also consistent with initial reports by the scale's developers, we did not find responses on the AAAS to be associated with income, social class, or level of education. These results provide further corroboration for the validity of the AAAS as a measure of the acculturation construct. To our knowledge, this is the first study, not conducted by the scale's developers, re-validating the psychometric properties of the AAAS.

We also replicated the relationship between acculturation and smoking status reported in previous studies (Landrine & Klonoff, 1996; Klonoff & Landrine, 1999). Consistent with those studies, we found a negative association between acculturation and smoking, with less acculturated African American women more likely to be smokers. Interestingly, the acculturation dimension that predicted smoking status in all three studies was Family Structure and Practices. According to the scale's developers, this dimension reflects the extent to which one's immediate and extended family subscribes to or adheres to practices, customs, and values (i.e. informal adoption) specific to African American culture (Landrine & Klonoff, 1994). If smoking is a behavior that is viewed as common, acceptable, and culturally sanctioned within one's early environment, then this experience may result in an increased risk for modeling smoking behavior. In support of this explanation, the smoking literature has found parental

smoking behavior and other family environmental factors to be significantly associated with children's current and future smoking behavior (Jackson, Henriksen, Dickinson, Levine, 1997, Jackson, Henriksen, Dickinson, Messer, Robertson, 1998; Bailey, Ennett, Ringwalt, 1993).

The final aim of this study was to explore the role of acculturation in BSE under-performance and over-performance. As mentioned previously, although BSE has yet to be definitely demonstrated to reduce breast cancer mortality, retrospective studies have shown BSE to be positively correlated with an earlier clinical and pathological stage of cancer diagnosis, earlier symptom presentation, smaller tumor size, and less axillary lymph node involvement (Foster et al., 1978; Foster & Costanza, 1984; Greenwald, Nasca, Lawrence, 1978; Hugley & Brown, 1981; Philip, Harris, Flaherty, & Josline, 1986). BSE has also been implicated as having utility as a method of cancer detection in between mammography screenings. Porter et al. (1999) found that 66% of tumors detected between mammography screening intervals were discovered via breast self-examination. Tumors detected during screening intervals were larger in size, more severe in disease stage, and more prevalent in younger women. Thus, BSE may be particularly beneficial as a method of detection for younger women whose disease progression is faster and more aggressive (Porter et al., 1999). Given the available evidence, BSE continues to be recommended strongly as a good health behavior and important breast cancer screening modality by the American Cancer Society (ACS, 1999) and the American Society of Clinical Oncology (Smith et al., 1999), respectively.

With regard to rates of BSE performance, fifty-one percent of the women in this study reported performing BSE at least once a month. This rate is consistent with the rate (49.7%)

reported in a random sample of low income, African American women ages 40 and over living in a Florida city (Mickey, Durski, Worden, & Danigelis, 1995) and also fell into the range (41% to 67%) reported by other populations of women 50 and older in the U.S. (NCI Breast Cancer Screening Consortium, 1990).

The BSE behaviors focused on in this study were BSE under-performance and BSE over-performance. While under-performing BSE has obvious implications for the utility of this screening modality, less appreciated are the potential drawbacks to over-performing BSE. It has long been recognized that over-performing BSE may decrease a woman's ability to detect gradual changes in the breast as well as induce cancer anxiety (Haagensen, 1952). Excessive BSE performance may also increase the likelihood of false positive findings which, in turn, may result in increased anxiety (Lerman, Kash, & Stefanek, 1994; Haefner, Becker, & Janz, 1989). Women may also use their over-reliance on BSE as a screening modality as a reason for opting out of or not adhering to other screening modalities such as mammography (Epstein & Lerman, 1997). Both under- and over-performance of BSE may then lead to diminished utility of this screening modality.

Results of the present study revealed significant associations between acculturation and BSE frequency. BSE under-performers were more acculturated, and consistent with that finding, a separate analysis found BSE over-performers were less acculturated. These "within ethnic group" associations with BSE frequency lend further support to the "between ethnic group" differences reported in a previous studies (Epstein et al, 1997; Vernon et al., 1991). Among a sample of 1,053 Caucasian and African American women, Epstein et al. (1997) found BSE over-



performers were more likely to be African American women while Vernon et al. (1991) found a higher rate of BSE under-performance among Caucasian women (71.3%) than African American women (61.8%). Results of the present study raise the possibility that these differences in BSE under and over performance by racial group may be, in part, related to acculturation.

In addition to identifying a relationship between acculturation and BSE frequency, we also explored the specific acculturation dimension that predicted BSE frequency. The Preference for African American Things, and Socialization subscales were significantly associated with BSE overperformance and underperformance. However, after applying Bonferroni corrections, the only dimension found to be significantly correlated was Preference for African American Things. This particular dimension has been interpreted by the scale's developers to reflect the extent to which an individual has a preference for African American newspapers, periodicals, music, activities, arts, and people (Landrine & Klonoff, 1994). Closer inspection of this dimension with item analyses (with Bonferroni corrections) in the present study revealed two items to be significantly associated with BSE underperformance: 1) "I read, or use to read, Essence magazine" and 2) "I read, or used to read, Jet magazine". Essence and Jet magazine are periodicals that specifically target an African American readership. Topics discussed in these magazines range from entertainment, politics, sports, current events, beauty, fashion, and health and medical issues that may be of particular interest or relevance to the African American community. BSE over-performance was significantly associated with one item: 1) "I listen to Black radio stations."

The common factor that would appear to link these three acculturation items relating to

BSE frequency is their function as mass media sources for the African American community. The role of mass media in publicizing breast cancer as a major health concern among women in the United States is evident. Turnbull (1978) found that a significant proportion of women increased their BSE performance from no performance/under performance to once a month or more as a result of the mass media surrounding Betty Ford's mastectomy. Additionally, women cited television/radio and periodicals/books as their number one and two sources of information, respectively (Turnbull, 1978). Among Latina women, Richardson et al. (1987) also found those who reported reading or hearing about (via television) the importance of performing BSE were more likely to perform BSE more recently and frequently. Based on these studies, it would appear that mass media is influential in breast cancer screening among ethnic minority women and women in general.

That an association was suggested between exposure to African American mass media and BSE frequency among African American women in the present study is entirely consistent with past research. Most notable is that women who under-performed BSE endorsed less exposure to African American mass media and women who over-performed BSE endorsed more exposure to African American mass media. African American women bear the biggest burden related to breast cancer as they have the highest rate of breast cancer mortality among women in the U.S (ACS, 1999). This differential impact may well be reflected and underscored in African American media sources as compared to the general mass media. Future research should compare breast cancer coverage between different media sources examining both the frequency of breast cancer articles appearing in issues as well as accuracy and clarity of information

presented in articles. It is also possible that less acculturated African American women may process breast cancer information differently than more acculturated African American women when exposed to African American media sources. This possible acculturation by media source interaction should be explored.

The evidence suggesting a specific pathway by which acculturation may be related to BSE frequency is a particularly intriguing aspect of the present study. Not only did a particular dimension of the AAAS (Preference for African American Things) predict BSE under-performance and over-performance, but a finer grained analysis revealed the specific media-related items within this dimension to be those associated with this health behavior. These findings suggest the general importance of identifying specific acculturation mechanisms that may influence the behavior of interest. Different health behaviors are likely to be associated with different acculturation dimensions. Consistent with this specificity model, the Family Structure and Practice dimension was found to be significantly associated with smoking status in this study and two previous reports (Landrine & Klonoff, 1996; Klonoff & Landrine, 1998), but not found to be related to BSE frequency in this study. Additional support for this idea can be taken from another study on acculturation and health behavior. Among young Asian American women, Tang et al. (1999) found the cultural barrier of modesty to be related to BSE, but did not find other aspects of culture or even a general measure of acculturation to be related to this behavior. On the other hand, among older Chinese American women, a general measure of acculturation was found to be a significant predictor of first time participation in mammography, clinical breast exam, fecal occult blood test, and sigmoidoscopy cancer screening, while other specific cultural factors (e.g. crisis orientation towards health, utilization of eastern medicine, lack of

family support) did not emerge as predictors for these screening behaviors (Tang et al., under review). Increasing the specificity with regard to the role of acculturation in health behaviors may thus assist us in targeting specific barriers for intervention.

Results from the present study have several clinical implications. Because the medical community has been focused predominantly on promoting breast cancer screening behavior, the problem of over-utilization or over-performance of screening has perhaps received less attention. When providing BSE education and instruction, especially for African American women and other high risk groups, health care providers may want to consider highlighting the diminished utility of both under-adherence and over-adherence to BSE guidelines.

Limitations to this study should be noted. Because the sample size was relatively small and women were recruited specifically from an inner city breast cancer screening center which served a largely economically disadvantaged population, our results can, of course, not be generalized to all African American women. It is possible that the acculturation process is different for African American women from this particular demographic and social strata as compared to other African American women. Considering our location of recruitment, it is likely that the prevalence of BSE under-performance and/or over-performance may be higher among women who do not receive BSE education and training as those in our sample did. We deliberately selected this sample for recruitment since all women attending the clinic were instructed in proper BSE technique as well as educated about breast cancer screening guidelines by African American health care providers. By holding BSE training, knowledge of BSE guidelines, and ethnic background of health care providers constant, we were better able to examine the effect of acculturation on BSE behavior, recognizing the heterogeneity among

African American women and that numerous factors may contribute to variability in acculturation and this screening behavior.

The study of African American acculturation is an emerging area of research. Initial results on the relationship between acculturation and smoking status and BSE frequency suggest that this concept has some utility in understanding some of the variability among African American women in health behaviors. Future studies should examine acculturation in relation to breast cancer screening modalities other than BSE. Given that African American women have the highest mortality rate for breast cancer and routine mammography has been shown to be effective in reducing breast cancer mortality by approximately 40% (Frisell, Lidbrink, Hellstrom, & Rutqvist, 1997), it would be important to investigate possible cultural variables are one of the factors associated with mammography utilization. Future research should also explore the role of the mass media in publicizing breast cancer screening information among African American women as well as other ethnic groups. While breast cancer impacts differently women of various ethnic backgrounds, how this information is presented and explained in the media may well influence women's screening behaviors.

As a construct, acculturation may provide useful information for enhancing our understanding of differences between and within groups that racial distinctions can not, although other variables (e.g. socioeconomic status) must also be investigated. Clearly, the value of the concept of acculturation in clinical research depends on how it is operationalized and utilized in understanding and predicting other health behaviors. By identifying specific acculturation components that facilitate or deter health behaviors, we may be better able to implement interventions to improve health status among different ethnic and cultural communities.

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**Table 1. AAAS Descriptive Statistics and Psychometrics (N=35)**

<i>AAAS</i>	Range	Mean	S/D	Median	Mode	<i>Standardized Alpha</i>
Preferences	15-71	50.54	16.33	55.0	53	.874
Family Practices	24-84	55.39	13.24	57.5	54	.688
Health beliefs	18-54	51.45	15.10	53.0	53	.823
Socialization	17-70	51.18	14.24	55.0	59	.741
Foods	16-68	40.13	13.95	40.5	26	.794
Religion	10-42	34.24	8.76	37.0	42	.837
Interracial Attitudes	7-49	29.46	11.63	29.5	15	.896
Superstitions	5-35	22.69	7.57	23.0	29	.710
Total AAAS	184-450	338.98	66.82	347.20	241	

**Table 2. Women with a history of smoking scored higher on AAAS (i.e., more traditionally African American)**

AAAS	Smokers N=16	Non Smokers N=19	F	p
Preferences	56.03	45.92	3.58	.067
Family Practices	61.02	51.56	5.14	.030*
Health beliefs	54.43	50.68	.60	.445
Socialization	53.75	49.56	.73	.397
Foods	44.95	37.34	2.90	.098
Religion	32.69	36.87	2.11	.155
Interracial Attitudes	34.33	26.54	4.71	.037*
Superstitions	25.31	21.40	2.80	.104
Summary Score	366.71	315.62	5.79	.021*

\*Significantly different at  $p < .05$

**Table 3. Women who Under Perform BSE Scored Lower on the AAAS (i.e., more acculturated) Than Women Who Over Perform BSE**

AAAS Scale	Under Performance Assessment Past year			Over Performance Assessment Past three weeks		
	Under Performers (N=17)	Others (N=18)		Over Performers (N=21)	Others (N=14)	
	Mean (S/D)	Mean (S/D)	F	Mean (S/D)	Mean (S/D)	Sig
Preferences	42.13 (16.11)*	58.48 (12.32)	11.46	59.88 (8.05)*	44.31 (17.60)	.004
Family Practices	54.55 (14.45)	57.05 (12.11)	.31	58.71 (12.18)	53.92 (13.72)	.298
Health beliefs	49.66 (14.14)	54.97 (14.18)	1.23	55.03 (14.38)	50.63 (14.17)	.376
Socialization	45.79 (15.27)	56.84 (11.35)	5.94	58.54 (9.12)	46.54 (15.22)	.010
Foods	38.01 (12.47)	43.47 (14.28)	1.45	45.28 (13.66)	37.84 (12.90)	.112
Religion	32.12 (10.41)	36.94 (5.85)	2.88	38.00 (4.15)	32.34 (10.07)	.055
Interracial Attitudes	28.53 (10.52)	31.58 (11.79)	.65	31.45 (12.24)	29.20 (10.54)	.566
Superstitions	21.56 (7.58)	24.72 (6.37)	1.78	25.71 (6.50)	21.50 (7.06)	.084
Summary Score	312.39 (70.38)	364.09 (53.79)	6.00	372.96 (41.84)	316.32 (71.45)	.011

\*Bolded numbers indicate Bonferoni corrected significance was reached ( $p < .05$  divided by 9 = .005).

Note: Re-analyses excluding women whose responses revealed long-term under performance and short-term over performance ( $N=4$ ) yielded an identical pattern of results.

**Table 4: BSE Under and BSE Over Performance, and Individual Items from the Preference for African American Things sub-scale**

AAAS Scale	Under Performance Assessment Past year				Over Performance Assessment Past three weeks			
	Under Performers (N=31) Mean (S/D)	Others (N=35) Mean (S/D)	F	Sig.	Over performers (N=43) Mean (S/D)	Others (N=23) Mean (S/D)	F	Sig.
Answers on sub-scales range from: 1 (Strongly disagree) - 7 (Strongly agree)								
13. I know how to play bid whist.	2.53 (1.99)	3.14 (2.45)	1.21	.274	3.00 (2.41)	2.77 (2.18)	.14	.707
14. Most of my friends are Black	5.22 (1.82)	5.62 (1.73)	.85	.361	6.13 (1.21)	5.06 (1.91)	5.76	.019
15. I feel more comfortable around Blacks than around Whites	4.25 (2.12)	4.40 (2.11)	.07	.787	4.47 (2.12)	4.25 (2.11)	.16	.686
16. I listen to Black radio stations	4.45 (2.17)	5.22 (1.71)	2.63	.110	<b>5.86 (1.51)</b>	<b>4.32 (1.98)</b>	<b>10.58</b>	<b>.001*</b>
17. I try to watch all the Black shows on T.V.	3.11 (2.28)	4.00 (2.30)	2.42	.124	4.60 (2.23)	3.03 (2.20)	7.55	.007
18. I read (or used to read) Essence magazine	<b>4.38 (2.33)</b>	<b>5.97 (1.56)</b>	<b>10.72</b>	<b>.001*</b>	6.13 (1.32)	4.74 (2.28)	7.12	.009
19. Most of the music I listen to is by Black artists	4.09 (2.19)	5.14 (1.68)	4.78	.032	5.26 (1.54)	4.32 (2.14)	3.41	.069
20. I like Black music more than White music	4.96 (2.18)	5.08 (1.90)	.06	.810	5.34 (1.69)	4.85 (2.17)	.88	.352
21. The person I admire the most is Black	5.22 (1.97)	5.89 (1.68)	2.17	.145	6.40 (1.06)	5.13 (2.02)	7.79	.006
22. When I pass a Black person (a stranger) on the street, I always say hello or nod at them	3.28 (2.20)	3.70 (5.33)	.64	.426	3.53 (2.04)	3.49 (2.19)	.00	.949
23. I read (or used to read) Jet magazine	<b>3.93 (2.01)</b>	<b>5.33 (1.52)</b>	<b>10.26</b>	<b>.002*</b>	5.46 (1.52)	4.25 (1.95)	6.68	.012

\*Bolded number indicated Bonferoni corrected significance was reached ( $p < .05$  divided by 11 =  $p < .004$ ).